NEW YORK CITY

TASK FORCE ON

WOMEN & AIDS

Policy Document

For additional copies contact:
National Women's Health Network
1325 G Street, N.W.
Washington, D.C. 20005

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1. THE NEW YORK CITY TASK FORCE ON WOMEN AND AIDS

The Task Force on Women and AIDS is made up of physicians, nurses, social workers, psychologists, researchers, administrators and advocates. We work with HIV infected and affected women in health centers, city and voluntary hospitals, jails, methadone clinics and the streets. We have joined together in an effort to create a comprehensive approach to the special needs of women in the HIV epidemic. Our commitment is to the provision of culturally appropriate, accessible health and social services that foster women's abilities to manage their health care needs.

This document is a collective effort with input from:

Kathryn Anastos, MD	Bronx Lebanon Hospital
Virginia Anderson, MD	SUNY-HSC Brooklyn
Marie-Lucie Brutus	Women's AIDS Resource Network
Monnie Callan, ACSW	Montefiore Medical Center
Barbara Cicatelli, MA	Cicatelli Associates Inc.
Awilda Cintron-Wolfert, MPH	New York State AIDS Institute
Elizabeth Cooper, JD	American Civil Liberties Union
Sharen Duke, MPH	Lower Manhattan Task Force on AIDS
Kathy Eric, RN	Montefiore Medical Center
Donna Futterman, MD	Montefiore Medical Center
Sally Guttmacher, Ph.D.	New York University
Susan Holman, RN, NP	SUNY-HSC Brooklyn
Sylvia Hutchinson, RN, MPH	New York City Department of Health
Audrey Jacobson, MD	New York City Board of Education
Patricia Kelly, FNP, MPH	Kings County Hospital
Sally Kohn, MPH	Public Health Consultant
Jean Langhans, RN, NP	St. Luke's Hospital
Carola Marte, MD	Beth Israel Medical Center
Janet Mitchell, MD	Harlem Hospital
Josie Morales, MA	Health & Hospitals Corporation
Louise Phillips, MD	SUNY-HSC Brooklyn
Anitra Pivnick, Ph.D.	Montefiore Medical Center
Meredith Platt, Ph.D.	Memorial-Sloan Kettering Center
Helen Rodriguez-Trias, MD	Private Consultant
Susan Rosenthal, ACSW	Private Consultant
Althea Smith, RN, Ph.D.	Health and Hospitals Corporation
K. Elsie Steinberg, MS	Morris Heights Health Center
Melanie Suchet, Ph.D.	St Luke's/Roosevelt Hospital Center
Rosalind Thompson, MPH	Harlem Hospital
Grace Wong, MD	Chinatown Health Center

(Institutions are listed for identification purposes and do not represent agency endorsement.)

2. INTRODUCTION TO THE ISSUES

Women's lives are changed by AIDS in many ways, as mothers, partners, friends and caretakers of people with HIV disease as well as persons who are themselves HIV infected. From the onset of the HIV epidemic, women's needs have been obscured by medical and social perceptions of AIDS as a disease primarily affecting gay, white men. Education and prevention services for women and poor, inner city communities were delayed while rates of infection increased. HIV infection among women is now increasing at an alarming rate. In New York City, the numbers have increased more than anywhere in the United States. There has not been a commensurate increase in public attention, resources or commitment to help.

The lack of response to women's increasing experiences with HIV infection and AIDS can be attributed to the triple jeopardy of gender, racial and ethnic, and class bias. However, while racism and classism play significant roles, female gender appears to be overriding factor which determines lack of resources, services and commitment.

All women are at risk of HIV infection and must be empowered to prevent HIV disease with efforts that recognize the diversity of their life experiences, cultural heritage, and the factors which influence HIV transmission. Indeed, sexism, racism, economic inequality, language differences, legal status and education, as well as substance abuse, domestic violence and the lack of affordable housing and child care have a major impact on the health status of women and their families. These long-term societal issues will require both short-term and long-term remediation strategies.

The prevention of HIV infection requires a perception of women not confined to their roles as mothers, partners, and care givers. HIV prevention is most effectively achieved through women's leadership in the design of policies and the implementation of programs. To accomplish these goals, society must develop a broader understanding of risk, the social factors which facilitate the transmission of HIV infection, the clinical manifestations of HIV in women, and the implications of the illness for women and their families.

3. SOCIAL ISSUES

3.1 PREVENTION

Public health prevention efforts structured predominantly through programs of disease surveillance are inadequate to the job of HIV prevention. Prevention efforts focussing on women and HIV infection should proceed from a perspective and vision which projects health concerns into the future so that we are not impaled several years from now on a narrow configuration of the problems and issues related to the character, definition, and impact of the HIV epidemic. Education and care must be provided for women in areas of high rates of infection, as well as for those women in lower incidence areas who do not currently believe themselves to be at risk. More importantly, education programs must be community-based, originating in a community in order to best suit the needs of its members.

Empowerment issues around the use of condoms are important. However, as long as condoms remain the only protection against the transmission of the virus during vaginal intercourse, women will have limited control. Intensive research is necessary to develop an effective viricidal cream and barrier protection that can be controlled by women.

Recommendations

- Make appropriate sex education a mandatory curriculum component at all levels of education, and should include discussions of all forms of sexual expression.
- Include eduction on unprotected sex and HIV infection and between drug use and HIV infection in school curricula, in university curricula, and in all health care settings.
- Include primary HIV prevention, drug use education, drug use assessment, and referral to drug treatment options in all primary care settings.
- Provide explicit, specific, safer sex education in all places where women are provided with health care and to women in all drug treatment programs.
- As part of voluntary programs, include efforts to educate sexual partners together and as individuals about high risk behaviors, safer sex, mutual monogamy, and open communication between partners.
- Provide education about the role of sexually transmitted diseases and the associated increased risk of HIV infection.
- Provide HIV prevention education in the larger framework of overall women's health care, including sexually transmitted disease prevention and treatment, family planning, gynecology and prenatal services.
- Make information available about the high risk nature of sex partners with genital ulcers, penile discharge and/or recent sexually transmitted diseases.
- Develop interventions to break the association between societal gender inequalities and the personal difficulties experienced by women in sexual relationships.
- Empower women about ways to protect themselves in sexual relationships.
- Expand and strengthen voluntary partner notification programs to prevent infection in seronegative partners and to protect the confidentiality of the infected person.

Recommendations (con.t)

- o Intensify research to develop viricidal creams and barrier methods of protection which are controlled by women.

- o Provide condoms and other protection as developed to women at health care, social service, and conjugal visit sites.

- o Include education concerning the transmission of sexually transmitted diseases and HIV between female sexual partners in all education programs.

3.2 FAMILIES AND HIV

AIDS can no longer be perceived as an individual disease affecting only the person carrying the virus. The effect of AIDS is felt by all family members, particularly partners and wives. In their pivotal family roles as mothers, sisters, daughters, aunts, mothers-in-law, and grandmothers, women are traditionally called upon to minister to ill family members as well as care for those who are not ill.

HIV threatens to disorganize families of all classes as increasing rates of infection compound previously existing problems. The chronic aspects of HIV disease call for long term care and support traditionally provided by women in their roles as nurturers and nurses. For all women, HIV illness can be an isolating and devastating experience as they care for infected family members. Women are central to poor families already strained by lack of adequate housing, accessible health care, child care, and financial resources. Poor women are further stressed by the chronic illnesses and losses of infected family members. For women who are themselves HIV infected, these difficulties are magnified many times over as they cope with their own infection and that of spouses, children and other family members.

Older women, in their roles as mothers and grandmothers, are faced with the unforeseen circumstances of caring for chronically ill children and their dependent children. These grandmothers face hardships related to the return of adult children, grandchildren who face the illnesses and deaths of parents, increased financial dependence because of illness, and the disruption of what otherwise might have been the first serene years of their lives.

Younger women, often infected themselves, are confronted by the physical and emotional needs of chronically ill partners and dependent children while coping with bouts of debilitating illness. Feats of ingenuity are required of HIV infected women in order to preserve their families during periods of intermittent hospitalization. Women facing separation from children and family members often forego treatment in order not to disrupt their families.

Recommendations

- o Direct social service agencies to maintain the integrity of the intact family unit; and where necessary, provide interagency directives.

- o Provide adequate financial and mental health supports for families with HIV infected members to maintain an intact family unit. Resources, including but not limited to respite care, homemaker assistance, family therapy, and child care must be made available.

- o Make available financial support for relatives caring for HIV infected family members and for foster children of HIV infected parents at the same level as for unrelated foster parents providing the same services.

3.3 HOUSING

The epidemic of HIV infection, particularly as reflected in women, provides a lens through which social dynamics are magnified. Women have pivotal economic roles in families in which there are HIV infected people. In low income families where men's work may be marginal and sporadic, women and children who receive public assistance frequently provide an economic base for the survival of the family. Home is where the family's central drama is played out; hence, issues related to housing are crucial to an understanding of the family burden which the AIDS epidemic has compounded for women.

New York City's housing policies during the past twenty years have resulted in a destruction of neighborhoods, a decimation of jobs and housing stock, and the growth of a sub-economy of abuse, crime and rootlessness, all of which form the substrata for HIV infection and AIDS among women and their families. The devastation of poor neighborhoods has led to the crumbling of local social and economic supports such as churches, medical care facilities and small stores. In response to the lack of affordable housing, families have doubled up and multiple families occupy single family housing units. Shelter systems and single room occupancy (SRO) hotel accommodations have become the predominant bureaucratic solution to the needs of people without homes, despite the fact that such living circumstances are unsuitable for women and children. Overcrowding and homelessness provide conditions for the tuberculosis, syphilis, and HIV epidemics of the 1980's and 1990's.

In the context of this severe housing deficit, patchwork solutions targeted for AIDS patients with housing needs are woefully inadequate. Although these solutions include several residences with social supports, most low income HIV infected persons have available to them only single rooms, shelters and SRO's. The few Tier II temporary family shelters do not adequately support family life or the needs of persons with disabilities.

Many women with AIDS and their families already bear the crushing burden of poverty, discrimination, ill health and multiple associated crises. Social policies which do not provide needed housing further erode the stability of families and entire communities.

Recommendations

- Make solutions to housing needs of women with HIV/AIDS a part of a broad social program to provide jobs, medical care, community, and home making supports as well as housing for low and moderate income families.

- Provide housing that must adequately accommodates families, with the understanding that for many Latino and African American women (whose numbers dominate AIDS statistics about women) the essential cultural context is the extended rather than the nuclear family.

- Provide governing mechanisms for women with HIV infection which safeguard the family's ability to remain together in appropriate housing following the death of the identified index HIV infected person.

- Provide housing for people with HIV infection that takes account of their increasing disability and provides necessary amenities (e.g., ramps, elevators, convenient laundry facilities).

- Include a spectrum of home assistance including child care, community day care, and respite care facilities in housing for women with HIV infection.

3.4 LEGAL ISSUES

All women who are HIV infected need legal representation and the protection of individual rights whether they are under the care of private doctors, outpatients in clinics, inpatients, caretakers of HIV infected persons, or members of groups such as drug users, sex workers, and prisoners whose civil liberties demand vigilant attention.

The legal issues affecting women that are brought into sharp focus by the HIV epidemic include: informed consent, confidentiality, guardianship and custody arrangements, prisoner's rights, living wills, the provision of health insurance, appropriate housing for homeless women who are HIV infected, and rights associated with reproductive activities such as timely abortion and protection against sterilization and abortion abuse.

The legal issues confronting women who are HIV infected reflect societal problems many of which antedate the HIV epidemic. Women's historical, on-going, day-to-day struggles are represented in legal concerns about the inclusion of women in clinical drug trials, gender appropriate case definitions of disease, the provision of appropriate drug treatment and medical care, the accessibility of health care, and the availability of child care, housing, and health insurance. Rooted in the societal disorders of economic and gender inequality, the problems which these legal issues represent take on even greater urgency in the context of HIV infection.

Recommendations

- o Provide legal counsel and services related to HIV infection for women in all health care situations including outpatient and prenatal clinics, inpatient settings, and testing and counseling services.

- o Make available legal counsel and services for HIV infected women with children who are minors and for those who are caretakers for HIV infected persons.

- o Provide legal services and representation for HIV infected homeless women, adolescent women, drug using women, and prisoners.

    - These services should include custody arrangements for minor children, wills, living wills, and health care proxies, and should be available in relevant languages.

    - The above legal services should be available on site at health care, social service, and housing facilities.

- o Expand the CDC definition of AIDS to reflect the spectrum of illness caused by HIV infection including gynecological manifestations of HIV.

    - All HIV related services which rely on the CDC criteria for evaluating the disabling effects of HIV disease should expand their criteria to include the spectrum of HIV disease.

- o Amend the Social Security Administration's disability evaluation criteria for HIV infected individuals to recognize the disabling effects of non-CDC designated impediments including but not limited to refractory vaginal candidiasis, chronic pelvic inflammatory disease, recurrent condyloma caused by human papilloma virus and cervical cancer.

4. MEDICAL ISSUES

4.1 HIV COUNSELING AND TESTING

Early detection and medical intervention are now providing many HIV infected women with improved morbidity and greater life expectancy. Although many women do not consider themselves to be at risk for HIV infection and therefore do not seek HIV testing and counseling services, improved medical treatment provides a strong rationale for all women to learn about their HIV serostatus.

The New York State Department of Health has mounted a new initiative to provide HIV counseling, testing and health related services for women. The first component is centered in the perinatal setting. However, it is important to remember that pregnant women make up only a small proportion of HIV infected women, that pregnancy lasts a relatively short period of time, and that the bulk of serious illness in women occurs outside pregnancy. Thus, the current initiative must be seen only as a first step to be greatly expanded if we are to reach a large percentage of HIV infected women.

Universal access to testing must be clearly distinguished from mandatory HIV testing. Calls for mandatory HIV testing, usually targeting women of child-bearing age, have arisen from many quarters including local, state and federal public health authorities. Mandatory testing violates the fundamental democratic principle of an individual's personal integrity. The knowledge that a clinic visit might result in unwanted HIV testing could influence a woman to avoid seeking care, even when pregnant. The New York State confidentiality and informed consent laws prohibit mandatory testing for these reasons.

Routine testing with the right of refusal is not a substitution for voluntary testing. This method operates as a proxy for mandatory testing. It is particularly dangerous for poor women who have fewer options about health care and for women who are not fluent in English. Furthermore, routine testing of newborns for the purpose of identifying HIV infected women violates informed consent and serves as a proxy for mandatory testing. Such routine testing also risks alienating the mother, who may then avoid health care for both herself and her child. Routine testing of newborns is only acceptable for purposes of blinded seroprevalence studies.

Recommendations

- Make available voluntary universal access to pre-test counseling to both confidential and anonymous testing.
- Do not replace voluntary testing as a method for identifying HIV-infected women with mandatory testing, or forms of proxy mandatory testing (e.g., routine testing with right of refusal, routine unblinded newborn screening or T-cell studies).
- Fully protect testing of newborns (other than blinded research studies) by confidentiality and the mother's informed consent.
- Do not alter or deny health care services because of a decision not to be tested.
- Ensure that HIV testing adheres to the spirit and the letter of the New York State confidentiality laws and that all medical providers be held to the law.
- Make funding available for the continued education (training the trainers) and update seminars of social workers, health educators, and counselors around HIV related issues.

4.2 PRIMARY HEALTH CARE

A large percentage of women with HIV infection in the United States live in inner city areas. Poor urban neighborhoods have traditionally had inadequate primary care services with resultant high infant mortality and adult morbidity. The lack of primary care services in these communities often leads women to seek care from hospital emergency rooms which offer fragmented care. Women need comprehensive on site services which include: primary care, as well as gynecological care, drug treatment, mental health, and support services. Women have had a history of unmet medical needs due to inadequate services.

Keeping seronegative patients uninfected is an important priority for the containment of the epidemic as well as for the individual's health. HIV prevention efforts are woefully inadequate when health care services are available primarily through emergency rooms and other acute care settings.

Primary health care services for HIV infected patients are not widely available. There is a lack of coordination of women's and children's infectious disease care, GYN care, and drug treatment services.

Drug detoxification and treatment programs for women are woefully inadequate. Successful modalities for the treatment of crack addiction and polydrug abuse have not yet been developed. Drug treatment and treatment options have traditionally been less available to women, particularly to pregnant women.

The psycho-social effects on women with HIV infection include ideas of contamination and/or stigmatization, social isolation, anxieties associated with sexual expression and identity, guilt at transmission to offspring, rage at having been infected by partners, and fears of disfigurement, disability, and death. Internal stresses are often compounded by the external pressures of limited financial resources, unstable housing, and unavailable child care.

Recommendations

- Facilitate increased availability of comprehensive primary care medical services in areas of high HIV seroprevalence through new federal, state, and local agency funding mechanisms and new incentives. These must not be funded at the expense of existing programs.

- Make available single site primary care services for HIV infected women. These should include all medical, gynecologic, drug treatment, and psychosocial services.

- Develop and coordinate adult and pediatric services, with the provision of on-site child care.

- Develop alternative and innovative models of primary care to include nonconventional sites where many women are already in contact with health-related services: family planning clinics, drug treatment programs.

- Include guidelines for routine gynecologic screening and parameters for the treatment of common gynecologic conditions which do not respond to ordinary therapy in written standards of care for HIV infected women.

- Remove barriers to the training and practice of Family Practitioners, most severe in the northeastern United States.

- Develop training initiatives in the primary care of HIV infection in Family Practice and other Primary Care residency training programs.

- Give priority to the training of professionals and paraprofessionals to work in the AIDS epidemic especially at community colleges and other institutions with high enrollments of minority and women students.

- Train health care practitioners treating women for gynecologic problems to recognize certain symptoms as indicative of possible HIV infection; on-going education and training of such practitioners is essential, as more is learned about the natural history of HIV disease in women.

- Encourage the training and practice of other health care providers, specifically Nurse Practitioners and Physician Assistants, in the primary care of HIV infection.

- Make case management for all HIV infected persons and their family members by interdisciplinary teams of physicians, nurses, and social workers an integral part of routine health care.

- Link all initiatives to target specific populations (e.g., child bearing women) for education, counseling, and testing for HIV infection to available and appropriate comprehensive primary care services.

- In areas of high HIV seroprevalence, link licensing of health care providers to mandatory continuing education about the prevention and primary care of HIV infection.

- Take active steps to strengthen community health centers as providers of HIV primary care. These should include enhanced reimbursement and provision of appropriate medical education for providers. These enhancements should be achieved without cutting back other Medicaid reimbursement formulas which support the delivery of sound primary care services.

- Make available individual, couple and family HIV related counseling to all women affected by HIV disease.

- Provide support groups for HIV infected individuals, their partners, care partners, and family members.

- Provide support groups for HIV negative individuals trying to maintain safer sex and drug use lifestyles.

- Provide bereavement counseling for surviving family members including children and adolescents.

- Provide enhanced counseling and education for women with psychiatric illnesses.

- Provide education to obstetricians, gynecologists and primary care providers about the medical indications for possible HIV infection and HIV testing.

4:3 RESEARCH/CLINICAL TRIALS

Information in the current medical literature concerning the natural history of HIV infection in women is inadequate. Studies of the natural history of this disease, including clinical manifestations and laboratory markers such as T-cell subsets, have not included female patients. Clinical trials of therapeutic agents have included few or no women subjects. There is little published information concerning the opportunistic infections occurring in HIV-infected women, and suggestions of a shorter survival time from diagnosis of AIDS to death in women have had inadequate follow up. Most early studies of HIV infection in women concentrated on perinatal transmission from mother to fetus and on infection rates in sex workers. HIV infected women have been viewed by the medical profession primarily as vectors of transmission to others (babies and the clients of sex workers), with little regard for their well-being as infected individuals.

The result of excluding women from clinical trials is that practitioners treating HIV infected women have a smaller body of scientific knowledge to use as a resource, and consequently less is known about the epidemiology of the disease in the female population. Preliminary evidence from several small studies suggests that many gynecologic conditions, including pelvic inflammatory disease (PID), vaginal candidiasis, human papillomavirus (HPV) infection, and cervical cytologic abnormalities are more common and more severe in HIV infected women.

The research situation has economic consequences as well. The U.S. Department of Health and Human Services has essentially chosen CDC defined AIDS as the eligibility criterion used to grant an HIV infected individual access to benefits. Further, access to Medicaid almost always is predicated on one's qualifying for social security benefits. But the opportunistic infections that make up a case definition of AIDS include no gynecological conditions. For example, esophageal yeast infection is included while vaginal yeast infection is not. Additionally, current recommendations for the provision for medical care to HIV infected women generally do not contain information about gynecologic care. And recommendations for counseling women about HIV infection do not usually target women with difficult to cure PID, vaginal candidiasis, HPV infection, and cervical dysplasia.

In addition, even when women are used as research subjects, the research process is often designed with inadequate attention to the needs of the subjects. The vast majority of HIV infected women are women of color who have little in the way of economic resources. They are frequently drawn into the research studies by incentives designed to attract poor women. The offer of small payments for participation as well as support services which are otherwise unavailable free of charge are unlikely to attract wealthier research subjects. Once women become involved as subjects, however, the continued availability of these "rewards" is dependent upon their compliance with the demands of the research protocol whether or not it is found to be intrusive or offensive. In addition, from the researcher's point of view, the services offered are a part of the research methodology. If at any time during the research project it is determined that the research is not proceeding satisfactorily, the services may be altered or eliminated to "correct the methodological approach." This, of course, is not to say that there are not some compassionate researchers. Indeed, some have been known to develop research projects as a means to provide HIV infected women with needed services.

The health care provided to pregnant, HIV infected women frequently attempts to protect the fetus from possible toxic effects of medication at the expense of appropriate treatment for the pregnant woman. For this reason, antiretroviral therapy and prophylaxis against pneumocystis pneumonia are frequently unavailable to HIV infected pregnant women. Currently available antiretroviral therapies have not been adequately tested for their effects on pregnancy.

Epidemiologic, clinical drug trials, and vaccine trials are necessary to determine the impact and effect of HIV infection and treatment on women. However, HIV positive and drug using women have been largely excluded from research trials. This has been the case historically and remains true for HIV disease. The principal effect of this exclusion is that gender specific differences remain unknown (e.g., menstrual

irregularities associated with AZT). However, merely removing women as an exclusionary category will not guarantee women's entry into clinical or epidemiologic trials. Entry into research protocols must be guaranteed for women. Meaningful incentives for involvement in research projects are necessary for women's participation.

Recommendations

- Include women, including those who use IV drugs, in clinical trials to permit an accumulation of a body of medical knowledge relevant to their treatment.

- Actively promote and fund research in the natural history of HIV infection in women through federal, state, and local funding agencies. Steps should be taken to insure that all funded research, including therapeutic drug trials, include women subjects and analyze data by gender, as well as by all participants.

- Make available incentives in the form of currently unavailable clinical or support services, child care, and transportation to women who participate in research designs.

- Make available the CDC, and state and local health department's data concerning opportunistic infections and survival times of women with AIDS.

- Fund research which explores appropriate drug treatment modalities for women, pregnant women, and women with children. Women must be made a priority for demonstration projects and research on the effects of various treatment options.

- Obtain full voluntary and informed consent for all individuals prior to their participation in clinical drug trials.
- Examine the existing body of clinical and epidemiological studies on HIV infection in women to see how the results can provide immediate benefit to women.

- Provide funds for the provision of long term services needed by HIV infected women rather than for repetitive descriptive studies.

- Commit funders to a continuation of the services to individuals once they are initiated in those cases where services are part of the research methodology even if the research methodology is altered as well as after the research is completed.

4.4 DRUG TREATMENT

Drug abuse in the United States has long been viewed as a criminal activity rather than as a condition requiring medical treatment and alterations in social conditions. Drug abuse is found in all socioeconomic classes. Although the HIV epidemic has encouraged public discourse about drug use, addicted women have yet to be provided with treatment which addresses the social causes as well as the physical manifestations of the disease of drug abuse.

The lack of appropriate drug treatment and drug treatment options is particularly evident in the lives of HIV infected, drug using women who must deal simultaneously with the effects of drug use, gender inequality, and the illnesses and stigma associated with drug use and HIV infection. Existing drug treatment programs are often overcrowded and based on a male model of care. They often lack health care, child care, and AIDS awareness programs, as well as the social support necessary to address the complex physical, psychological, and behavioral changes which accompany successful drug addiction treatment. Moreover, drug treatment opportunities for pregnant women are extremely limited.

Women who have drug use problems require a comprehensive program of integrated services in order to address these problems, as well as HIV infection, risks of HIV infection, family issues, and issues of personal empowerment.

Recommendations

- Create a comprehensive drug treatment program which includes separate facilities for women as well as attention to distinct issues of women and children within existing drug treatment programs. Provide residential detoxification and crises services for women, including pregnant women, with provision for their children.

- Create within this program, specific drug appropriate outpatient and inpatient treatment to address polydrug addiction.

- Include the following components in drug treatment programs: social services, primary care (GYN care, STD diagnosis and treatment), prenatal care, AIDS awareness, HIV counseling and voluntary testing, family and individual therapy, support groups, child care, legal services, parenting skills, aftercare, and empowerment opportunities such as GED provision, job counseling, and job placement.

- Include drug addiction specialists and concrete services in primary care settings.

5. ETHICAL ISSUES

5.1 CONFIDENTIALITY

Assuring confidentiality of HIV testing is the legal obligation of health providers and the legal right of those tested. As routine HIV education becomes universally offered to women using health services, a greater number will undergo HIV testing. Providers of HIV testing will be responsible to assure the strictest confidentiality of these tests and test results.

The release of medical records or test results conveying an individual's HIV serostatus can result in discrimination which can be catastrophic to one's personal and work life. On the other hand, providers' knowledge of an individual's HIV status can enhance medical treatment and entitlement opportunities. It is therefore incumbent on the provider to discuss the liabilities and benefits of disclosure with the infected person and come to joint agreement for releasing test results.

New York State Confidentiality Law provides strict protection of one's HIV status; however, the law allows a broad spectrum of service providers to be informed of a person's serostatus. It is therefore essential that each institution develop its own explicit policy and protocol for confidentiality and disclosure of medical records containing information about HIV status consistent with state law. Each institution must enforce its policy with strict adherence. Employees who breach confidentiality should be held accountable and subject to appropriate measures, including termination of employment.

Recommendations

- Offer anonymous testing at health care sites as an alternative to available confidential testing.
- Protect strict confidentiality of medical records and enforce sanctions for the disclosure of confidential records.
- Require that each provider agency create a tracking system to insure that disclosure of confidential information does not occur except within the bounds of the law. Any such disclosure must be necessary, limited in scope, and documented.
- Require that each provider notify other recipients of confidential information, in writing, of the prohibition against further disclosure of that information.
- Insure patient consent prior to the disclosure of any HIV related information (including the fact that a test for HIV antibodies has been performed). The patient must first be told the name or job title of the recipient of such information, as well as the purpose for which it will be provided.
- Establish persuasive penalties for disclosure of confidential information for all agencies and institutions.

5.2 PARTNER NOTIFICATION

Voluntary partner notification can be an effective tool for reducing the spread of HIV and providing intervention early in the course of disease. The protection of confidentiality in these programs is important because violations of confidentiality have resulted in discrimination and loss of jobs, homes, and friends. The protection of confidentiality is particularly important for women because of their vulnerability to possible physical, emotional, and financial abuse. Any program which is not voluntary and confidential will serve to deter people from HIV education, testing, and treatment.

Recommendations

- o Initiate mechanisms and program in all health care institutions to assist HIV-infected people in partner notification and provide counseling for couples and family members as well as for individuals.

- o Make available partner notification only on a strictly voluntary basis.

- o Any contacts should be made only by the patient herself or, with her informed and voluntary agreement, by a provider or Notification Specialist (Public Health Office) trained in crisis counseling and knowledgeable of the personal circumstances of the partner and the relationship.

- o Train Partner Notification Specialists, frequently called Public Health Officers, as trained crisis counselors capable of handling the typically strong reaction resulting from a notification. They should be in a position to provide preventive education, brief counseling and assist in identifying and making appropriate referrals.

- o Providers should encourage all HIV infected clients to participate in voluntary partner notification programs.

5.3 REPRODUCTIVE RIGHTS

Abuses of women's fundamental rights to control their reproductive lives are common. Forced abortion, denied abortion, pressure not to become pregnant, and forced sterilization are ways in which women's rights to reproductive autonomy are violated. Current Centers for Disease Control guidelines state that HIV infected women should be encouraged to "postpone" childbirth. This position sets the stage for efforts to pressure women into abortion and/or sterilization. Current evidence indicates that approximately 30% of children born to HIV infected women in the U.S. will themselves be infected. This percentage is significantly lower in studies from European countries.

Lack of vigilance regarding reproductive rights encourages the possibility of the criminalization of childbirth by HIV-infected women. At this time, fourteen states have bills pending which would criminalize willful transmission of HIV infection. Although no statutes have been proposed to criminalize perinatal transmission, such an application is not inconceivable, especially as we see efforts to prosecute women for "delivering" drugs to their newborns during gestation or at birth.

Incongruously, HIV-infected women who choose to terminate pregnancy are denied Medicaid funding in a growing list of states (now a majority). In the climate of the 1990's, women who are HIV infected and choose to terminate pregnancy face increasingly restrictive state abortion laws. In addition, HIV-infected women of childbearing age may be pressured by providers to submit to sterilization as a method of preventing transmission to offspring. HIV-infected women of childbearing age have the right to decide whether to carry a pregnancy to term and whether to select sterilization as a method of contraception.

Non-directive counseling for women seeking abortion and sterilization information requires that the counselor act as facilitator and the patient as the decision maker. Directive counseling, in which the counselor's judgment is imposed upon the woman, is inappropriate and coercive. Non-directive counseling for HIV-infected women should provide accurate and unbiased information on the risks of transmitting HIV, on the prognosis of infected children, and on all available options and support services. This is a professional, legal, and ethical obligation regardless of a woman's serostatus, economic status or ethnicity.

Recommendations

- o Maintain pregnancy, abortion, and sterilization as an individual decision, free from coercion and counselor bias and to be made only after all information is considered, including an accurate presentation of the risk of perinatal transmission.

6. RECOMMENDATIONS FOR SPECIFIC GROUPS OF WOMEN

6.1 WOMEN OF CHILD BEARING AGE

All women in New York State, of all ages and parity, and of every stage of life, are at risk for HIV infection. Reduction of HIV infection requires a perception of women based upon all aspects of female experience, a perception which includes, but does not rely entirely upon women's unique reproductive capacity.

In the context of the HIV/AIDS epidemic, women who are HIV infected and determine to bear children are often perceived as irresponsible. In particular, women who are HIV infected or perceived to be at risk for infection are vulnerable to coercion and discrimination, often in the form of policies that mandate prenatal testing or aggressive abortion and/or sterilization counselling. Rather than infringing upon women's reproductive rights, efforts to reduce perinatal transmission of HIV are best expressed in efforts to reduce the transmission of AIDS among women.

It is important that information about HIV infection and its modes of transmission be available when women come in contact with the health care system, as well as in locations frequented by women (e.g., pediatric clinics, churches, day care centers, drug treatment programs, beauty parlors, etc.).

It is equally important that women have access to comprehensive primary health care services, which would address reproductive and general women's health issues in an ethnically and culturally appropriate manner. Different and varied social, cultural and personal experiences must be respected and recruited in efforts to reduce transmission.

Recommendations on behalf of Women of Child Bearing Age

- Protect and respect every women's right to decide herself whether or when to bear a child.
- Train counselors to counteract biases, including a presumption of control over the patient's choices, in order to safeguard the patient's right to control her own reproductive life. Whatever decision the patient makes regarding the pregnancy or a birth control method must be supported by the counselor.
- Make available abortion or sterilization regardless of a woman's serostatus or her ability to pay for the procedure.
- Insure access to necessary services for themselves and their children to women choosing to continue pregnancy, regardless of their HIV status or that of their newborns.
- Make support services available to a patient whatever decision she makes.

6.2 HOMELESS AND PRECARIOUSLY HOUSED WOMEN

There are a great many homeless women and children. While there are no accurate statistics on homelessness among women, advocates estimate that on any given night 30,000 people stay in shelters and another 30,000 sleep in the street in New York City. It is difficult for a woman to take control of her life or her health when she is moving from place to place, unable to meet her most basic needs.

Many homeless women do not know their HIV status and have no idea why they should be tested, or how. Daily survival needs such as food and shelter take priority over health care. Because of these overwhelming pressures, homeless women are apt to use emergency services as their primary source of

health care. HIV risk reduction, especially the use of condoms, may not be an option for women who trade sex for food or drugs. Circumstances of sexual violence often make risk reduction an impossibility. While some services for HIV infected homeless women are available, in the absence of visible symptoms women are often sent back to the streets, and the cycle of hopelessness begins again.

The New York City Human Resources Administration currently provides enhanced HIV services only to persons who are symptomatic of HIV infection. At present, an HIV infected woman whose child with AIDS dies can lose the enhanced rent subsidy and be forced into the shelter system or on the streets.

Recommendations on behalf of Homeless and Precariously Housed Women

- Formalize the New York City Human Resources Administration's policy to provide housing assistance, including the enhanced rent subsidy, to individuals with HIV infection, regardless of whether they are symptomatic in order to prevent women from entering shelters.

- Develop residential drug treatment options for homeless women who are substance users (and therefore at high risk of HIV infection) that address the needs of these women and their children.

- Include in these options residential settings for women and their children, with treatment modalities that are appropriate for women who may have caregiving responsibilities for their children and/or extended family members.

- Include in such treatment: building self-esteem, vocational training, HIV risk reduction and parenting education, including guidance on caring for children and infants who require special care due to the addiction history.

- Develop alternative housing arrangements for high risk and HIV infected women who are homeless, currently in the shelter system, or ready to go back into the community from drug treatment settings.

    - One option would be group home settings that house three to five women and their children, with a site coordinator who would assist the women in developing the skills to negotiate the system and become independent. Such housing would also allow for the delivery of home, health services to HIV infected women, which may help to delay disease progression and to prevent unnecessary hospital stays.

- Equip shelter settings with on-site or, at a minimum, readily accessible health and social services that address the needs of HIV infected individuals based on their functional status. Persons with symptomatic HIV infection cannot be appropriately cared for in shelter settings and should be given the highest priority for more permanent housing.

- Provide HIV risk reduction information routinely in shelter and SRO settings, preferably integrated with other services, such as WIC pre prenatal education.

- Provide counseling and testing services routinely, with primary care made available.

- A wide range of ancillary services are essential for HIV infected women in the shelter system. Caseworkers/managers should assist the client in obtaining adequate nutrition, buddy services, legal assistance services, HIV and parenting education. Mental health services should also be integrated with other services to address the needs of homeless and sheltered women. Referral networks to ensure timely and easy access to these services should be established.

- Assign a Human Resources Administration caseworker to each case within one week of the receipt of the required application. Decentralization of the approval process should be considered as a method to alleviate long delays in the process leading to the assignment of a caseworker.

- Outstation HRA Division of AIDS Services (DAS) caseworker staff at hospitals and other community-based organizations serving women affected by HIV. Deployment of staff to such locations will make DAS services more easily accessible to those most in need and will help to ensure continuity of services. At present, for example, persons residing on Staten Island must travel to Manhattan to the closest HRA office.

- Assign a primary case manager to all HIV infected women to help the client respond to immediate crises, and to aid her in developing the skills needed to negotiate the system for herself and her children.

- Establish reimbursement for care management services under COBRA for all Medicaid clients, including follow-up home visits.

- Make available a set amount, based on the Office of Mental Health COBRA model, between $2,000 and $4,000 a year per client, for the purchase of such items as telephone services, babysitting, and transportation, at the discretion of the case manager, which will assist the woman in caring for herself and in maintaining her independence.

- Require health care providers to have training on the disease of addiction and the realities associated with homelessness.

6.3 WOMEN IN PRISON

The issues faced by HIV infected female inmates are similar to the issues faced by all infected women. Among the most pressing issues for women inmates are health care, confidentiality, and child custody.

The New York State Department of Corrections (DOC) estimates that at least 20% of women entering prison are HIV infected. Many women hesitate to seek testing in prison or jail because of the fear that their results will not be confidential. Furthermore, monitoring T-cell levels is not a routine part of prison health care, and repeated requests for specific medical attention often results in a breach of the inmate's confidentiality. Too often, inmates identified as having HIV disease are segregated from the rest of the prison population. The result often is a severe diminution to access to the general programs and services otherwise available in a prison setting.

The myriad of issues for HIV positive women with children are severely compounded by their imprisonment. Women inmates need legal and social service assistance in choosing among options such as guardianship, wills and adoptions in planning for the care and custody of their children.

HIV infected women inmates awaiting release require extensive advocacy and social service assistance in order to obtain adequate housing, entitlements, psychosocial support, and health care for themselves and their children.

Recommendations on behalf of Women in Prison

- Provide all Department of Corrections personnel and all inmates with HIV education.

- Enforce the New York State Confidentiality Law in all prisons and jails.

Recommendations (con't.)

- o Make available HIV services in all prisons and jails, and develop standards of care monitored by outside organizations.

- o Develop special programs for HIV positive inmates who are mothers which provide counseling, parenting education, and legal services for inmates, their children and other family members.

- o Implement programs that facilitate family/child visits for women who are imprisoned.

- o Eliminate segregation that is not requested by the inmate or necessary to deliver health care services.

- o Provide equal access to prison programs and visitation to infected and non-infected alike.

6.4 IMMIGRANT WOMEN

Since December 1987, all immigrants who apply to become temporary or permanent residents of the U.S. are required to take an HIV antibody test as part of their application for permanent residence. Some immigrants applying under the "amnesty" program or as refugees are eligible to apply for a waiver of the HIV test requirement; however, few waivers have been granted to date. Immigrants are often not provided the pre-test and post-test counseling required under applicable New York State law.

Both the law and the implementation of the testing program for immigrants are problematic because many women are unaware of their risk of HIV infection and illness. Immigrants' problems are further compounded by language barriers, an inability to access health care, and fear and isolation. For some, having lived, worked, and borne children in the United States, returning to their countries of origin would deprive them of emotional and social support. Unfortunately, both abroad and at home, HIV infection and illness are sources of stigmatization and social isolation.

Recommendations on behalf of Women who are Immigrants

- o Include culturally appropriate pre- and post-test counseling in all HIV testing conducted by the Immigration and Naturalization Service.

- o Include bi-lingual staff in health services for immigrants to insure accessible care.

- o Immigrants must not be denied HIV health services nor their residency status jeopardized if they seek health care.

6.5 LESBIANS

Very little data is available on the number of lesbians who are HIV-infected or have AIDS. Ignorance of lesbian sexuality leads many providers to assume that lesbians never have sex with men, and that risk reduction education and counseling about male to female sexual transmission are unnecessary. The Centers for Disease Control (CDC) defines "lesbians" for data surveillance purposes as women who have had sexual relations only with other women since 1977. Yet the reality is that many women who identify themselves as lesbians do have, or have had, sexual contact with men in the last fourteen years. Moreover, the CDC warns that cunnilingus is not a "safer sex" activity but relevant information is disseminated largely to heterosexual communities and not to lesbians. Lesbians are also at risk for HIV infection because of drug use. It is essential that lesbians not be excluded from primary prevention efforts, and that the CDC collect health statistics on cases of HIV infection among lesbians.

Recommendations on behalf of Lesbians

- o Include female-to-female transmission in risk assessment data collection systems.
- o Develop education and counseling efforts which include safer sex information for lesbians.
- o Train providers to provide non-judgmental risk reduction education and counseling for lesbians.

6.6 SURVIVORS OF SEXUAL AND DOMESTIC VIOLENCE

Domestic violence and sexual assault, traditionally private crimes, are far more prevalent than previously acknowledged. In the course of their lives, 1 in 3 American women will be raped. In over half of all American marriages, men are physically abusive. Women also face abuse in the context of lesbian relationships. Women victimized by family violence or rape require counseling and special assistance.

Threats of physical violence make it difficult for women in abusive relationships to negotiate safer sex practices with their partners (such as the use of condoms). HIV counseling, testing, and partner notification, as well as education in safer sex practices must be cognizant of the constraints faced by battered women, and must address strategies of empowerment.

Recommendations on behalf of Survivors of Sexual and Domestic Violence

- o Develop the capability among primary care and other health providers to offer physically and sexually abused women HIV counseling and education services tailored to their specific needs.
- o Provide services through HIV/AIDS service providers which address the legal, medical and emotional needs of women and children who have survived physical and sexual violence.
- o Provide support services in rape crisis and domestic violence programs which address the impact of HIV/AIDS on survivors of violence.

6.7 ADOLESCENT WOMEN

Experimentation with sex and drugs places adolescents at heightened risk for acquiring HIV infection. Most sexually active adolescents do not use contraceptives; only approximately one quarter consistently use birth control and of those most do not use condoms. Furthermore, adolescent females are at even greater risk for HIV infection and AIDS than adult females. For example, the ratio of AIDS cases among adolescent males and females is 1:1, compared to an 8:1 ratio among adult men and women. While the number of cases of CDC defined AIDS among adolescents appears to be relatively low, the majority of AIDS cases among people ages 20-29 years were most likely infected with HIV during their teens.

Adolescents in general are at risk for high levels of depression, anxiety, and other unpleasant mood states. Depressed youths often use street drugs to relieve these psychological symptoms. Assessments of runaway adolescents reveal a high incidence of unrealistic self perceptions, sexual abuse, psychological distress, and atypical experiences of psychosexual milestones. Long term effects include depression, suicide attempts, and impaired self- esteem. Homeless teens are at extremely high risk for HIV infection due to the survival strategy of trading sex for money or drugs. Adolescents who live independently from their parents are a disenfranchised population. It is extremely difficult for homeless youth to access medical and social services because they are often unable to meet the fee for service or parental consent requirements. Parental consent may often be harmful. Finding out one's HIV status may further expose terrible secrets with regard to sexual identity, sexual abuse, the trading of sex for money, and drug addiction.

Whether teenagers live with their parents or live independently, the high rates of IV drug use and HIV infection in inner city neighborhoods place young people in these neighborhoods at increased risk.

Adolescents lack access to drug treatment programs, health care, clinical drug trials, housing, mental health services, and legal services independent of their parents or guardians. Although early medical care is recommended for HIV infected persons, many adolescents do not have access to age-appropriate health and social support services, largely due to many parental consent requirements.

Recommendations on behalf of Adolescents

- Develop alternative education-prevention methods for youth currently not served by schools or health care centers. Also develop educational programs that help teens truly appreciate that they face grave risks by participating in certain behaviors.
- Educate parents and communities about HIV-related risks for adolescents; buiid ties with parent and community groups to generate support for AIDS education with a focus on empowering parents to advocate on behalf of their children.
- Assure free distribution of condoms in all high schools and colleges.
- Develop and expand effective drug prevention and treatment programs for youth.
- Expand youth programs which provide economic, recreational and/or educational alternatives to drug use; these programs should be based in the community.
- Encourage or create joint efforts between health providers and youth-serving agencies to make all services more accessible.
- Develop HIV medical services specifically for adolescents in all boroughs.
- Expand the ability of school-based clinics to perform reproductive examinations.
- Policies affecting adolescents should be reviewed in an effort to document those which deny access to services.
- All testing for adolescents must be offered with adequate counseling by specially trained staff, and with the guarantee of health and social services for those who are HIV infected.
- Educate providers about adolescent sexual issues, AIDS issues and health care issues.
- Establish research and drug trials for the adolescent population, including those to monitor the natural history of HIV disease in this population.
- Develop and evaluate media campaigns and interventions. A message of empowerment through responsible choices should be utilized.

6.8 SEX WORKERS

Throughout the course of the HIV/AIDS epidemic, female sex workers have received an inordinate amount of attention — attention that has focused primarily on sex workers as vectors of infection. These women are commonly deprived of access to entitlements, social services, and health care. A substantial percentage are themselves past or present drug users or the sexual partners of drug users, and thus face a risk of HIV infection. Services for this population must be non-judgmental and address the realities of sex worker's lives.

Recommendations on behalf of Sex Workers

- Provide adequate housing for all low-income women, including sex workers, so that lack of a permanent residence does not deprive women of access to social services and entitlements or unduly encourage a woman to trade sex for money if it would not otherwise be her choice to do so.

- Provide appropriate substance abuse treatment facilities for sex workers in a safe and nonjudgmental environment in which women can address the issues of drug use, sexual abuse, and risks for HIV infection.

- Make available HIV counseling and testing services to all women in a manner accessible to them, so that early medical care can be obtained if they are infected.

- Insure that sex workers have access to a full range of supportive and nonjudgmental health care services. When entering the health care system, many sex workers conceal the nature of their occupation, fearing disapproval or even punitive measures. This frequently leads to inadequate and inappropriate treatment.

6.9 DRUG USING WOMEN

Women who use drugs represent a cross section of the population including all classes, races/ethnicities, and occupations. Women's primary risks for HIV infection stem either from their own injection drug use, or that of their sexual partners. It is currently estimated that at least one half of the 200,000 injection drug users in New York City are HIV infected. Of women diagnosed with AIDS in New York City, 60% have histories of injection drug use, and another 22% are the sexual partners of injection drug users. HIV infected drug using women often care for HIV infected family members and children while dealing with their own HIV-related illnesses.

The inability of drug using women to access needed drug treatment and support services is compounded by the current lack of gender-appropriate drug treatment and treatment options. Many drug treatment programs are based on a male model of care for heroin users, and a majority of these programs do not provide services for pregnant women or women with children. There is an extraordinary shortage of drug treatment placements available, especially for pregnant women.

In addition to a lack of treatment opportunities and gender appropriate drug treatment, HIV infected, drug using women face even greater barriers to care. Once having enrolled in treatment, HIV positive women are often not provided with primary care, prenatal care, family counseling, support groups, or legal or social services. Most programs do not provide STD treatment or gynecological care, the lack of which has serious consequences for HIV infected women. As pivotal family caretakers, HIV positive, drug using women are in need of supportive services as well as programmatic assurances of primary and prenatal care.

Recommendations on behalf of Drug Using Women

- Include HIV counseling and testing, support groups, and social and family services for HIV infected women in all drug treatment programs.

- Integrate drug addiction services into existing prenatal and other primary care services in order to insure all drug dependent women the opportunity to address their addiction.

- Keeping in mind the time frame of pregnancy as the period of heightened motivation, immediate enrollment in appropriate treatment should be available to all drug using women.

Recommendations (con't.)

- o Residential drug treatment should include options for residence with children and programs should be designed which are compatible with women's psychological needs, and which provide parenting skills training, continuing education, and job training.

- o Provide primary care and prenatal care for HIV positive drug using women on site in all drug treatment programs.

- o Include in methadone treatment programs options for cocaine/crack treatment as well as methadone-to-abstinence tracks for women desiring to detoxify from methadone. Methadone treatment should include child care provisions and empowerment opportunities.

- o Conduct research about the effects of cocaine/crack use and institute programs implementing the results.

- o Develop effective, age appropriate drug treatment programs and treatment options for adolescent drug users. Within these programs, provide comprehensive primary care services which include intensive HIV education and prevention components.

- o Develop community based youth programs that provide economical, recreational and/or educational alternatives to drug use.

6.10 MENTALLY ILL AND DEVELOPMENTALLY DISABLED WOMEN

The mentally ill population figure disproportionately among the unemployed and unemployable, the addicted and the homeless. Because they are a community without a voice, they and their needs are easily ignored. Mentally ill persons are falsely perceived as sexually neutered and as healthy apart from their mental disability. A survey of the mentally ill in New York City shows an HIV infection rate of 5.9% (compared to a citywide rate of 2.9%). The seropositive rate for mentally ill Afro-Americans is 10.7%.

The mentally ill and developmentally disabled, by the nature of their illness, often have impaired judgement and learning ability, impaired social relations, and poor impulse control. Most are susceptible to impulsive or coerced behavior in sexual and drug using experiences. Many are at increased risk for becoming infected because a belief in invulnerability is characteristic of their thought disorder.

Women who are mentally ill or developmentally disabled face the same problems of HIV risk and infection as other women but with poignant complication. As a community whose power is routinely denied, mentally ill and developmentally disabled women are vulnerable to victimization in every form, from theft and fraud to sexual coercion and rape. Past or present abuse is common. Succeeding in interpersonal negotiations, such as those required to prevent infection, is even more problematic than for healthy women. As emotionally disabled women, their own self- endangering behaviors are compounded by socially condoned exploitation.

Mentally ill and developmentally disabled women are unlikely to socialize in ways that bring them in touch with accurate information or education about HIV infection. They need special attention and counselling to understand both the risks of HIV infection and ways to ameliorate those risks. However, the many who are also drug users are excluded from most psychiatric clinics and are excluded from nearly all drug treatment programs. It will not be possible to reduce HIV transmission and disease among mentally ill women unless this grave neglect is corrected.

Recommendations on behalf of Mentally Ill and Developmentally Disabled Women

- Provide all mental health workers with HIV training.
- Make available HIV education, counselling and testing services in all inpatient and outpatient mental health facilities. Referral for appropriate and accessible medical care for HIV-infected mentally ill and developmentally disabled women must also be available.
- Develop special teaching and intervention strategies for mentally ill and developmentally disabled women.
- Insure that drug using women have access to psychiatric treatment at all inpatient and outpatient facilities, including mental health clinics and hospital-based psychiatry clinics.
- Insure that mentally ill and developmentally disabled women have access to drug treatment programs, both residential and day.
- Make available suitable housing, including special residential facilities, to women with functional impairments because of their psychiatric diagnosis.